California State Council on Developmental Disabilities

2007-2011 STATE PLAN

"The Council advocates, promotes & implements policies and practices that achieve self-determination, independence, productivity & inclusion in all aspects of community life for Californians with developmental disabilities and their families."

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About the State Council

Councils on Developmental Disabilities are established in each state through the federal Developmental Disabilities Assistance and Bill of Rights Act. This Act also creates state Protection and Advocacy Systems, Centers for Excellence, and Projects of National Significance. Each entity has a federally assigned responsibility designed to improve services for individuals with developmental disabilities and their families, and enhance independence, productivity and inclusion.

The California State Council on Developmental Disabilities (SCDD) is established by state and federal law as an independent state agency to ensure that people with developmental disabilities and their families receive the services and supports they need. The Council is uniquely composed of individuals with a developmental disability, parents and family members of people with developmental disabilities, and representatives of agencies that provide services to individuals with developmental disabilities. The Council consists of 29 members appointed by the Governor, with individual and family consumers representing a minimum of 60 percent of the membership. By law, Chairs of the Council and its committees are individuals with developmental disabilities or members of their families.

The Council's vision is that Californians with developmental disabilities are guaranteed the same full and equal opportunities for life, liberty, and the pursuit of happiness as all Americans. Toward that vision, its mission is to advocate, promote and implement policies and practices that achieve self-determination, independence, productivity and inclusion in all aspects of community life for Californians with developmental disabilities and their families. In California, the Council funds 13 Area Boards on Developmental Disabilities. The Area Boards are located throughout California to assist the Council in carrying out its mission and ensure that local needs are identified and met.

About the State Plan

Consumers know best what supports and services they need to live independently and to actively participate in their communities. SCDD advocates for coordinated, comprehensive community services, individualized supports, and other forms of assistance and works to ensure full access to these services. Federal law requires the Council to identify ways to improve and increase services for individuals and their families, and to submit these to the federal government in the form of a five year State Plan.

The State Plan identifies goals and objectives that the Council intends to achieve with its $6.6 million in annual federal funding. The Council’s goals and objectives are achieved by State Council and Area Board activities and Community Program Development Grants. The Plan is developed with extensive community input prior to its approval by the Council and submission to the federal government. Federal approval for the Council’s 2007-2011 State Plan was received on October 30, 2007. In accordance with Federal law the Plan is updated each year based on public review and public comments received during June and July.

At the time the 2007-2011 State Plan was submitted there were 25 Council Members and 4 vacancies. Those Council Members and their appointed representations are listed on the next page.

COUNCIL MEMBERS

Kim Belshé, Secretary
(Designee: Eileen Cubanski)
California Health and Human Services Agency

Sascha Bittner, Chair
Consumer Representative from Area Board 5

Catherine T. Campisi, Director
(Alternate: Gary Kuwabara, Chief Deputy)
California Department of Rehabilitation

Lora Connolly, Acting Director
(Alternate: Nicole Smith, Acting Chief Deputy)
California Department of Aging

Theresa Delgadillo, Director
(Alternate: Julie Jackson, Chief Deputy)
California Department of Developmental Services

Shirley Dove
Non-governmental Agencies Representative

Marcia Good, Vice-Chair
Parent Consumer Representative from Area Board 10

Eric Gores
Consumer Representative At Large

Robert Jacobs, M.D., M.P.H., Director
University of Southern California (USC) Childrens Hospital Los Angeles
University Center for Excellence in Developmental Disabilities Education, Research, and Service

Yvonne Kluttz
Consumer Representative from Area Board 11

Randi Knott
Parent Consumer Representative from Area Board 3

Claudia Lima
Parent Consumer Representative from Area Board 1

Susan Luzzaro
Parent Consumer Representative from Area Board 13

Sunny Maden
Parent Consumer Representative of Developmental Center Residents and Families

Ted Martens
Parent Consumer Representative from Area Board 9

Emily Matlack
Consumer Representative At Large

Stacy McQueen
Parent Consumer Representative from Area Board 12

Jack O'Connell, Superintendent of Public Instruction
(Designee: Dan Boomer, Ph.D.)
California Department of Education

Brad Putz
Consumer Representative from Area Board 6

Laura Ramos
Consumer Representative from Area Board 4

Olivia Raynor, Ph.D., Co-Director
Tarjan Center at University of California Los Angeles (UCLA)
University Center for Excellence in Developmental Disabilities Education, Research, and Service

Sandra Shewry, Director
(Alternate: Rich Bayquen, Chief Deputy)
California Department of Health Services

Steve Silvius
Parent Consumer Representative from Area Board 8

Cindy Simon
Parent Consumer Representative At Large

Julie Wilsted
Consumer Representative from Area Board 7

Vacancy
Protection and Advocacy, Inc.

Vacancy
Senate-Nominated Consumer Representative

Vacancy
Assembly-nominated Parent Consumer Representative

Vacancy
Consumer Representative from Area Board 2

Environmental and State Service System Factors

Environmental Factors Affecting Services

The Administration on Developmental Disabilities asks the Council to describe how economic, social, political, and litigative factors impact persons with developmental disabilities and their families in California.

High Cost of Living

California remains one of the least affordable states in which to live. Three of the five most costly cities in the nation are in California (San Francisco, Los Angeles and San Jose). This has a significant impact on the ability of consumers to live independently.

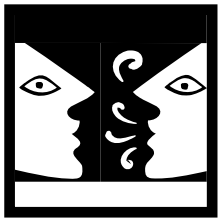
The September 2005 median housing price in California was $543,980. The annual income needed to purchase the median priced home with a 20 percent down at 6.33 percent interest payment is $134,200. It is no wonder that only 15 percent of all California households could afford to buy a median-priced home, less than a third of the nationwide affordability index of 49 percent. Forty-four percent of all Californians spend more than 30 percent of their income on mortgage payments, the highest percentage in the nation. The cost of housing has caused many Californians to move to lower-priced communities and endure commutes of one, two or even three hours each way. In addition to the human cost in terms of lost time, the dramatic rise in fuel costs has reduced the financial benefit of living elsewhere.

With the cost of home ownership so far out of reach for the majority of Californians, with or without disabilities, the ability to live in the community relies heavily on rental housing. According to December 2005 data from the National Low Income Housing Coalition, Californians need an average hourly wage of $22.09 (working 40-hours-a-week) to afford the rent on a two-bedroom home. In San Francisco (the state's highest

cost area) the full-time hourly wage needed is even higher at $29.54. This has a clear impact on both consumers and the workforce who provide the consumers with the services and supports needed to live as independently as possible.

This disparity results in a greater reliance on subsidized housing for low income Californians. As a result, the waiting list for subsidized rental housing in California is measured in years, and in some high cost areas it may take up to ten years to reach the top of the list. Even then, there is no guarantee a consumer will find housing that accepts "Section 8" rental assistance vouchers and whose rents can be afforded. If someone is unable to find a rental within a designated period of time, that Section 8 voucher expires and it goes to the next person on the list. Adding to the potential of further delay, many of the original affordable housing subsidy contracts or regulatory agreements are nearing the end of their obligation periods and could potentially be converted to market value properties, resulting in even less availability.

Diversity



The California Endowment identifies 224 different languages spoken in California, with 91 languages spoken in the Los Angeles School District alone. The U.S. Census defines a racial or ethnic majority as one that represents more than 50 percent of the population. There is no ethnic or racial majority in 20 of California's 58 counties (2004 US Census data).

An analysis of the 1994-2004 Department of Developmental Services (DDS) caseload reflects the same trend. While the percentage of white consumers in the DDS caseload has experienced a 10-year decline from 49.4 percent to 42.4 percent, the percentage of Hispanic consumers has increased from 24.3 percent to 31.8 percent during the same time period. More than one in five consumers (22.89 percent) has a primary language other

than English. This trend is even higher among Hispanic consumers where 58.9 percent report Spanish as their primary language.

The U.S. Census Bureau defines linguistic isolation as any household where no one over the age of 14 speaks English well. Using this definition, one of every four Spanish-speaking California households and three of every ten California households speaking Asian/Pacific languages are linguistically isolated.

Cultural diversity is not limited to language differences. Public testimony at Council Hearings stated that even among consumers and families who speak English; there will be cultural differences that must be respected in the design and delivery of services. The cultural diversity of the State and of the developmental disabilities community underscores the need for culturally and linguistically competent outreach, providers and professionals, services and information.

Aging

The arrival of the oldest of the Baby Boomer generation at age 60 was extensively reported in 2006. The same national trends concerning the Baby Boomer generation pertain to California consumers with developmental disabilities.

In addition to the overall numbers of people in this age group, the life expectancy for individuals with developmental disabilities has increased dramatically over the same time period. This can be demonstrated by the consumer figures for the 52-61 year old age group. While the 10 year (December 1994-December 2004) increases in the overall DDS caseload is 68.9 percent, the increase in the 52-61 year old age group more than double that growth rate at 145.3 percent.

One of every five DDS consumers is now at least age 42 (20.53 percent in October 2005 CDER data). This impacts consumer housing needs as the parents' own aging-related health needs increase and the parents' housing needs may change. While roughly two out of every three consumers ages 18 to 41 live with their parents or guardian (63.72 percent), there is a marked shift beginning at age 42, and by age 52, the percentages are more than reversed, with just over one in five consumers (21.85 percent) living with parents or guardians. Strategies to address such issues as aging-related medical supports and licensure categories must be adopted to ensure the right to continue to choose where and with whom to live throughout the lifespan.

Healthcare

Access to quality healthcare is one of the most frequently recurring themes in of any type of barrier identification or needs assessment, regardless of the primary topic.

Whether the primary issue is employment, developmental center closure, community inclusion, education, or transportation, the issue of healthcare access is frequently brought up as a major ancillary barrier. Access to appropriate dental care and mental health professionals, neither of which are on the list of federally-required Medicaid benefits, are of particular concern.

The State's Medi-Cal program is the largest federal Medicaid program in the country. While California has 70 primary care providers for every 100,000 in the overall population, there are only 46 primary care providers for each 100,000 Medi-Cal recipients (source: California Healthcare Foundation, Medi-Cal Facts and Figures, January 2006). This disparity is even more pronounced in comparing the number of medical specialists. While the overall population has 10 specialists per 100,000 population, there are only 4 specialists per 100,000 Medi-Cal recipients. This has a

significant impact on healthcare access for individuals with disabilities, many of whom require access to one or more medical specialists, including: neurologists, orthopedists and cardiologists. If surgery is needed, the access is further reduced, with only 5 surgical specialists per 100,000 recipients compared to 15 per 100,000 for the overall population. Medi-Cal Managed Care is now available in 22 of California's 58 Counties and, if implemented properly, could improve healthcare access for people with developmental disabilities.

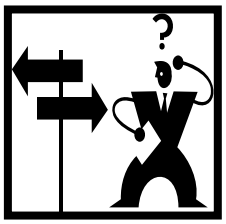
In addition to lack of mental health providers accepting Medi-Cal, other barriers pose additional challenges, including: lack of education of mental health providers in the area of developmental disabilities and misperceptions that people with cognitive impairments cannot benefit from mental health services. As a result, providers may be unwilling to provide services, regardless of funding availability.

California continues to expand its use of Federal Home and Community Based Services (HCBS) Medicaid waivers to reduce the usage of institutional care whenever appropriate. But, while HCBS waivers can increase the numbers who are eligible to live in the community, community inclusion remains an unattainable goal if the workforce to provide the community-based services and supports does not exist. It is critical that there be enough direct service providers to provide the community based services and supports needed for consumers to live successfully in the community.

The State Service System

The FederalGovernment asks Councils to provide a summary of the Council's review and analysis of the state service system for people with developmental disabilities, including reference to relevant interagency initiatives and any specific eligibility barriers to services.

Overwhelming Complexity



Overwhelming complexity is a defining characteristic of California's government services, beginning with State Government. While smaller states may find it easier to group similar services and functions into one department, the sheer enormity of California has resulted in a "complex web of organizational entities" consisting of 11 agencies, 79 departments and more than 300 boards and commissions.

In 2005, Governor Schwarzenegger's own California Performance Review Commission reported that "California's state government is antiquated and ineffective. It simply does not mirror the innovative and visionary character of our state. Instead of serving the people, it is focused on process and procedure. It is bureaucracy at its worst — costly, inefficient and in many cases unaccountable."

But for Californians with developmental disabilities and their families, the complexity of State government is not the end of the bureaucratic maze that must be negotiated in obtaining services. The most recent statistics from the California Department of Finance show the following local governmental structures: 58 counties, 479 cities, and 1,053 public school districts consisting of 9,397 public schools.

In addition to the public schools, the California Department of Education has certified more than 1,000 nonpublic schools and agencies to provide special education services to students with disabilities. There are also an estimated 2,300 independent special districts

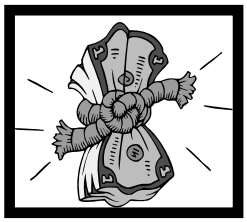
in California, providing “generic” services on which consumers rely, ranging from police and fire to public transportation to utilities to parks and recreation. Some special districts provide a single service, while others provide multiple services to a regional population.

This complexity is no less true, and is often actually compounded, within the developmental disabilities service system. It is multidisciplinary, multi-departmental, and multi-governmental (federal, state, region, county, city) in both form and function.

The California Department of Developmental Services, through its community service system of 21 separate private nonprofit regional centers, is responsible for meeting the needs of California’s consumers. Under California’s Lanterman Act, consumers and families have an entitlement to services. If the Individual Program Plan (IPP) identifies a necessary service, it is the responsibility of the regional center to provide it – but only if it cannot be obtained through other means.

The state mandate in the developmental disabilities service system is to exhaust all other service options before relying on the developmental services system. Other state and local agencies provide “generic” services that may or may not be available to individuals with developmental disabilities. These other agencies do not enjoy entitlement status and therefore may not be motivated to provide services to consumers with developmental disabilities if regional centers are obligated to fill in the gaps. This disparity in departmental missions can lead to delays in service, frustration, inefficiency, and confusion, even among state agencies, as to which agency is appropriately responsible for which services.

Open-Ended Entitlement vs. Capped Appropriation



California, the only State with an entitlement, is obligated to serve all consumers eligible under the California definition. The funding to provide these services, however, has a capped, or fixed, budget appropriation.

As a result, funding for services is not necessarily tied to the number of individuals in the system and the types of services they require. This disparity can create conflicting missions within the regional centers, as they are charged with identifying all needed services for recipients while operating within the constraints of a fixed annual appropriation.

Funding/Rates

The wage crisis for direct support workers is by no means unique to California; however, when coupled with the State's high cost of living, it represents a major systemic barrier.

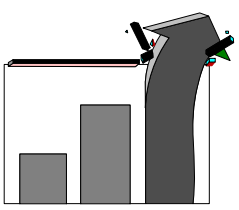
It has been reported to the Council that individual placement for supported employment is almost non-existent for new clients due to the rates of reimbursement, especially job development. The rate of reimbursement of $1,000 for job development and placement comes to about $3 per hour for agencies. Public testimony to the Council stated that as a result, many Supported Employment agencies have been unable or unwilling to accept new clients. The impact is that regional center clients end up in more expensive, more restrictive, less satisfying and less inclusive programs. The 2006-2007 State Budget included funding to double the rate from $1,000 to $2,000. It is too soon to know when and how this will impact the consumers who can benefit from Supported Employment services. SCDD will monitor implementation of this important system improvement.

The Governor's proposed 2006-2007 State Budget included a 3 percent cost of living increase for community vendors of the regional centers. The State Council has gone on record as supporting the proposed 3 percent cost of living increase to community vendors of the regional center, recognizing it as an important first step toward a stronger community system. The State Budget also included an additional 2 percent increase for direct care staff in some day programs and work activity programs.

Funding and rates are an underlying issue in each of the other topics identified by the State Council. Rates paid to direct providers impact the provider's ability to afford housing, which, in turn, may cause a shortage of workers as they turn to better paying professions. It also impacts the ability to attract and retain culturally competent workers and fund culturally sensitive programs that adequately meet the needs of diverse consumers. The aging of consumers' parents, resulting in the increasing shift to out of home care as the consumer ages, has a clear funding implication since housing is not a funded service when consumers live with their families.

Access to healthcare for individuals receiving Medi-Cal is definitely impacted by reimbursement rates. A physician providing health care services to an individual on Medi-Cal receives only 59-69 percent of the rate that would be paid for the exact same procedure if the individual were on Medicare. The 2006-2007 Budget includes a Medi-Cal provider rate increase. Its impact on healthcare access for consumers is not yet known.

Autism



The developmental disabilities service system was originally designed, staffed and funded primarily around the needs of individuals with cognitive impairments. Between December 1994 and December 2004,

the number of California DDS consumers with cognitive impairments declined from 87.6 percent to 78.2 percent. By far, the category with the largest growth during that same time was autism, growing 360 percent, from a caseload of 5,775 to 26,576. As of the first quarter of 2006, that number continues to rise, with an April 2006 caseload of 30,181.

The service and support needs of individuals with autism, whose challenges may include flight-risk, communication difficulties, hyper-sensitivity to certain sights and sounds, and aggressive and/or self-injurious behaviors may require not only additional programs, but a redesign of existing programs and staffing patterns.

Consumers ages birth to 21 currently make up more than half of the DDS caseload, and include 84 percent of the entire autism caseload. Up to age 22 many of the consumers' services and supports are funded by Special Education via Individual Education Programs (IEPs). Once the individual ages out of the education system, the majority of costs are the responsibility of the DDS Regional Center System. As these children grow to adulthood, the cost implications become significant. A 2005 DDS analysis of FY 2003-04 data showed a per capita DDS cost 254 percent higher for 22-41 year olds with autism when compared to DDS costs for 3-21 year olds with autism. The DDS per capita cost for 22-41 year olds with autism is also significantly higher than for the same age consumers without autism ($29,631 vs. $16,790). Planning for the fiscal impact to DDS as an increasing number of consumers age out of the Special Education system is critical.

The 2006-2007 State Budget funds the Governor's Autism Spectrum Disorder (ASD) Initiative, which will: provide training to clinicians and other professionals to implement ASD Best Practice Guidelines for Screening, Diagnosis, and Assessment; develop/disseminate best practice guidelines and state-of-the-art information on evidence-based treatments/interventions for persons with ASD; establish state/regional

ASD resource centers; and establish positions at the regional centers to coordinate with families and professionals seeking ASD information, guidance and resources.

System Reform

Two major initiatives that will significantly change the California service delivery system are in the final planning stages and will be implemented during the course of this five-year plan.

The first is the statewide expansion of the Self-Directed Services Program, originally expected to be available in fall of 2006. As described in Department of Developmental Services (DDS) materials:

> The Self-Directed program is “A means by which individuals who are eligible for state developmental disabilities services are empowered to gain control over the selection of services and supports, that meet their own needs." The Self-Directed Services program will "Enhance the ability of a consumer and his or her family to control the decisions and resources required to meet all or some of the objectives in his or her individual program plan."

California has previously piloted self-determination projects, but the project is now expanding statewide. While a federal Independence Plus waiver is being submitted for all those who qualify, an important component of the program is the allocation of additional state funding for those who are not waiver-eligible.

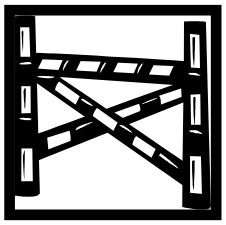
The planned implementation of Self-Directed Services has been delayed due to difficulty in consolidating several data systems into a unified system that can accommodate the necessary components of self-directed services.

The second major system reform concerns the upcoming closure of Agnews Developmental Center. What sets this closure apart from others is its extensive multi-year collaborative planning, including building the capacity of the community services and supports system to successfully meet the needs of the Developmental Center residents.

Three major pieces of legislation were enacted to assure that the proper community supports were in place before the closure of the Developmental Center. AB2100/SB643 allowed Bay Area Regional Centers to secure and assure lease payments for the Bay Area Housing Plans Homes. This legislation also allowed a new category of services, known as Family Teaching Homes. SB962 created a pilot program of community care homes for adults with special health care needs. The final piece of the puzzle, AB1378, will allow state developmental center employees to provide community services and supports for a period of time in order to provide for a smooth transition for the Developmental Center residents. This includes an outpatient clinic, opened May 1, 2006, that allows Agnews' staff to provide outpatient medical and dental care when generic services are not available or accessible.

Procedural delays in implementing the programs authorized in these pieces of legislation have delayed the expected closure date to June 30, 2008.

Barriers for Unserved and Underserved:



The Federal Government asks the Council to "list and describe racial/ethnic groups that may be unserved/underserved and describe the barriers to their receipt of supports and services. You may identify barriers specific to a particular racial/ethnic group you have selected, identify general, overall barriers applicable to all racial/ethnic groups selected, or both. List and describe any other unserved/underserved group(s) and describe the barriers that impede full participation of this group(s). Examples of such groups are religious groups, rural populations, those excluded from eligibility for particular services, particular types of disabilities)"

Consumers with Multiple Disabilities

The systemic issues previously identified are compounded for consumers with multiple disabilities. The need to access more than one medical specialist and public service system can increase barriers to services, including possible disagreements over which agencies are responsible for providing which services. Testimony at State Council meetings has identified particular difficulties for consumers who also have mental health needs.

Consumers with multiple disabilities can face additional barriers if accessibility planning is only done with the primary disability in mind. A mental health program may not be prepared for the physical access needed by an individual in a wheelchair, or consumers with cognitive impairments who are also blind may find there are no consumer friendly materials written in Braille. Consumers with developmental disabilities who are also deaf/hard of hearing have also reported communication barriers in accessing programs.

Linguistic and Cultural Accessibility

As previously identified, one of every four Spanish speaking California households, and three of every ten households speaking Asian/Pacific languages are considered linguistically isolated – having no one in the household over the age of 14 who speaks English well.

Geographic Accessibility

Although California is home to three of the nation's ten largest cities, it is also home to numerous rural or geographically isolated communities. Alpine County, the State's smallest, is home to only 1,242 residents and has no incorporated cities in the entire County. San Bernardino County alone covers the same geographic area as the combined states of Maryland, Delaware, New Jersey, and Rhode Island. It is a shorter distance to drive from Washington D.C. to Chicago, Illinois, than to drive the length of California. This has major service implications, especially for consumers who need specialty healthcare and other services. Consumers and families have testified to the Council that they have six hour drives each way to reach medical specialists, not including time spent in the doctor's waiting room and the examinations and treatment. This would be a difficult schedule for anyone, but is especially difficult for those with disabilities who are frequently on specific medication and feeding schedules.

State vs. Federal Definition

California is home to an estimated 661,107 residents who meet the federal definition of developmental disabilities. In contrast, the Department of Developmental Services follows a more restrictive state definition and has a current caseload of just over 200,000. Without the benefit of entitlement to services, there are service barriers for those who meet the federal but not state definition. This is particularly true for adults with disabilities. During their schooling years, the educational system will fund many of the needed services, regardless of whether the individual falls under the federal or state definition.

Community Services and Opportunities:

The Federal Government asks the Council to "provide a summary of the extent to which community services and opportunities related to the areas of emphasis directly benefit individuals with developmental disabilities. Include information on assistive technology/services and rehabilitation technology, current resources and projected availability of future resources to fund services, and health care and other supports and services received in ICF(MRs) and through Home and Community Based Waivers."

Assistive Technology (AT)/Rehabilitation Technology

Public testimony on assistive technology identified these issues:

- Consumers/families have not been educated on the availability of assistive technology;
- Families report reluctance by professionals to consider assistive technology for those with cognitive impairments;
- Even when assistive technology is provided, consumers, families, providers and staff are not properly trained in its usage, care and maintenance;
- Consumers/families need to try out various pieces of equipment to determine the best individual match before an expensive purchase is made;
- As consumers become comfortable with the use of their AT equipment, they need additional training to utilize their equipment to its maximum potential;
- Technology evolves so quickly that equipment can become obsolete so Assistive Technology services must include periodic replacement of equipment;
- The Internet is increasingly the source of community access and participation but the ongoing monthly cost of an Internet Service Provider is a hardship for consumers with limited incomes.

SCDD is now represented on the Assistive Technology Advisory Council.

Current Resources and Projected Availability of Future Resources to Fund Services

California received much greater than anticipated revenues in spring 2006. As a result, the State appears to be on a more solid fiscal path than in the past several budget years. In addition to paying down the State's indebtedness, which improves its ability to fund needed health and human services in the future, the enacted budget includes an increase in Med-Cal provider rates, and the cancellation of a prior year five percent Medi-Cal provider payment reduction. Other issues impacting current and future resources are identified elsewhere in the Plan.

Health Care and other supports for ICF/MRs and HCBS

As noted elsewhere in this Plan, California continues to expand its use of Federal Home and Community Based Services (HCBS) Medicaid waivers to reduce the usage of institutional care whenever appropriate. But, while HCBS waivers can increase the numbers who are eligible to live in the community, community inclusion remains an unattainable goal if there aren't enough workers to provide the community-based services and supports. The shortage of healthcare professionals, particularly specialists, who accept Medi-Cal, impacts consumers who have no other method of receiving appropriate healthcare. Access to appropriate dental or mental health services is particularly problematic. Additional information can be found under the Healthcare and Funding/Rates topics under Environmental and State Service System Factors.

Waiting Lists

The Federal Government asks the Council to "provide the name of the waiting lists in your state and the number of the individual with developmental disabilities on those lists. Provide a brief review of the waiting lists in your state."

California, the only state with an entitlement, is obligated to serve all consumers eligible under the California definition. Previously, anyone with one of five diagnoses (mental retardation, autism, epilepsy, cerebral palsy, or conditions requiring services similar to mental retardation) & a substantial disability was eligible for regional center services, but the term substantial was subject to interpretation & could vary from area to area.

In March 2004 California clarified its definition of substantial disability, consistent with functional limitations in federal law. In addition, however, in California the age of onset must be before 18, and is still limited to the diagnoses specified. As a result, the California definition continues to be more restrictive than the federal definition.

Ideally, there should be no waiting lists for entitled services; however, there may be people waiting for services in areas where services are difficult to develop, or where generic services have been cut & developmental disabilities services are not yet developed. Developmental disabilities entitlements do not preclude waiting lists for generic services and supports, many of which struggled to meet service demands even before budget cuts.

The most common unmet needs identified by regional centers who responded to SCDD were: affordable, accessible housing, including more HUD certificates; services for children and adults dually-diagnosed with mental illness and developmental disabilities; transportation, particularly cross-jurisdiction; employment services that result in jobs with decent salaries and benefits; and increased self-advocacy and family supports.

Although the situation is improving, California is still recovering from huge multiple budget shortfalls of previous years. While the last three State Budgets spared direct services for consumers with developmental disabilities as much as possible, many generic services on which consumers rely were not so fortunate. Even among those who still provide services, budget cutbacks and staff reductions may result in less frequent services.

The shortage of healthcare providers willing to accept Medi-Cal patients continues to further limit availability of medical & dental services. Even when patients are not officially on waiting lists, the shortage of doctors who accept Medi-Cal can mean waits of up to six months for some appointments. The healthcare shortage extends beyond doctors. Consumers who receive recurring therapy (i.e. speech, physical & occupational) may not appear on waiting lists because they are being seen. In reality, however, they may only receive a fraction of the sessions from which they could benefit due to the shortage of therapists to serve the size of the caseloads.

AREAS OF EMPHASIS, GOALS AND OBJECTIVES

The Federal Government asks the Council to decide what Areas of Emphasis it will focus its activities and resources on during the five years of the State Plan. For each Area picked the Council must give reasons as to why it is each Area is important for people with developmental disabilities and their families in California.

The Council must also identify Goals and Objectives that it will work on within each Area of Emphasis. The federal government says that the Council shall implement the State plan by conducting and supporting the following advocacy, capacity building, and systemic change activities:

- Outreach
- Training
- Technical Assistance
- Supporting and Educating Communities
- Interagency Collaboration and Coordination
- Coordination with Related Councils, Committees and Programs
- Barrier Elimination, Systems Design and Redesign
- Coalition Development and Citizen Participation
- Informing Policymakers
- Demonstration of New Approaches to Services and Supports
- Other Activities

The following pages contain information about each selected Area of Emphasis.

Community Supports

Why is this important?

Access to a full range of appropriate community supports is a critical component in achieving full community inclusion.

Community Supports Goal 1:

Californians with developmental disabilities and their families are fully included in all aspects of community life.

What will the Council try to achieve toward this goal?

CS 1.1 By September 30, 2011, 1300 Californians with developmental disabilities will participate in service and volunteer opportunities of their choosing.

CS 1.2 By September 30, 2011, 2500 children and youth with developmental disabilities will participate in inclusive community activities through Council efforts.

CS 1.3 By September 30, 2011, 500 adults with developmental disabilities will participate in community life in meaningful and fulfilling ways through Council efforts.

Community Supports Goal 2:

Californians with developmental disabilities will experience increased inclusion and independence through the use of assistive technology.

How will the Council try to achieve this goal?

CS2.1 By September 30, 2008, the Council will work collaboratively with appropriate entities to develop and implement a plan to educate staff and service coordinators about computer and assistive technologies and how these tools can be used to increase consumer and family control, choice, and flexibility.

CS2.2 By September 30, 2008, the Council will work collaboratively to develop and implement a campaign to educate consumers and families about computer and assistive technologies and how these technologies can be used to maximize their developmental and educational potential.

CS2.3 By September 30, 2008, the Council will advocate for policies that secure free (or low-cost) Internet access for adults with developmental disabilities.

CS2.4 The Council will work collaboratively on methods to ensure that staff/educators/providers who interact with the consumer are also properly trained in how the AT equipment works and is used.

CS2.5 By September 30, 2009, the Council will advocate for the periodic re-evaluation and re-training of consumers periodically as their proficiency with the equipment increases

CS2.6 By September 30, 2008, the Council will promote the creation of locations where consumers and their families can try out a variety of assistive technology choices to choose the equipment best suited to their individual needs.

Community Supports Goal 3:

Californians with developmental disabilities have full and equal protections in all state and federal emergency preparedness/homeland security programs.

How will the Council try to achieve this goal?

CS3.1 By September 30, 2008, The State Council will collaborate with other state and federal agencies to promote methods to ensure that all Californians with developmental disabilities and their families have a personal emergency plan, and will advocate for the inclusion of this information in all Individual Education and Program Plans (IEP/IPP).

CS3.2 By September 30, 2007, the State Council will participate in a statewide Task Force to ensure that the needs of Californians with developmental disabilities and their families are included in all emergency preparedness training and services.

CS3.3 By September 30, 2008, the State Council will work collaboratively to convene a California Emergency Management Conference patterned after the June 2006 federal "Working Conference on Emergency Management and Individuals with Disabilities and the Elderly."

CS3.4 By September 30, 2007, the State Council will participate in California's Emergency Preparedness Vulnerable Populations Subcommittee.

How will the Council report/measure its success?

CS01: The number of individuals who receive formal/informal community supports through SCDD efforts.

CS02: The number of dollars leveraged for formal/informal community supports through SCDD efforts.

CS03: The number of programs/polices created/improved for formal/informal community supports through SCDD efforts.

CS05: The number of people trained in formal/informal community supports through SCDD efforts.

Education and Early Intervention

Why is this important?

Families, especially those with limited English proficiency, experience delays in information and access to Early Intervention services. There is a gap in services and supports between the ages of three and five as children and families are caught between the Early Start and Regional Center systems. Families of children who meet the federal definition of developmental disabilities but are not eligible for regional center services need information on services and supports for which their child may qualify. Many students have limited access to an appropriate education. The increasing numbers of students with autism has impacted their educational opportunities for students as schools are unable or unwilling to provide appropriate programs. Opportunities for people with developmental disabilities to be an integral part of their school community are limited by limited access to assistive technology. There are limited opportunities for adults with autism and other developmental disabilities who want to pursue post-secondary education.

Education Goal 1:

California infants and toddlers reach their developmental potential and families have the necessary supports to provide for their family member's special needs.

How will the Council try to achieve this goal?

ED1.1 The Council will promote policies that give infants and toddlers and their families access to culturally appropriate and timely diagnosis, services and supports to maximize developmental potential and strengthen families.

Education Goal 2:

Californians with developmental disabilities have control, choice and flexibility in the education they receive.

How will the Council try to achieve this goal?

ED2.1 Every year 2000 students with developmental disabilities and their families will have information, advocacy and support in multiple languages to receive an appropriate education through Council and Area Board efforts.

ED2.2 The Council will replicate successful technical assistance models to increase the participation of 100 children per year in inclusive preschools.

ED2.3 By September 30, 2008, the Council will promote effective programs/policies that successfully transition students with developmental disabilities to post-secondary opportunities.

How will the Council report/measure its success?

ED01: The number of students whom have the education and support they need to reach their educational goals through Council efforts.

ED02: The number of infants and young children that have services/support needed to reach developmental goals through Council efforts.

ED05: The number of dollars leveraged for education.

ED06: The number of education programs/policies created/improved.

ED07: The number of post-secondary institutions that improve inclusive education.

ED10: The number of people trained in inclusive education.

ED12: The number of parents or guardians trained regarding their child's educational rights.

Employment

Why is this important?

People with developmental disabilities are significantly under-represented in the workforce, despite decades of employment and pre-employment services. Children with disabilities are not given an equal opportunity to learn of and dream about possible future careers, especially in school settings. The growing shortage of supported employment services, made worse by reimbursements that do not cover the providers' costs, provide an additional barrier to gainful employment. Limited access to assistive technology and education/training for consumers, co-workers, and employers further limit employment opportunities.

Employment Goal 1:

Californians with developmental disabilities obtain, succeed and advance in employment consistent with their interests, abilities, and needs.

How will the Council try to achieve this goal?

EM1.1 By September 30, 2011, 650 Californians with developmental disabilities will obtain paid employment or self employment of their choosing.

EM1.2 By September 30, 2011, the Council will work collaboratively to improve California regulations/policies to ensure a smoother transition from education to employment.

EM1.3 By September 30, 2011, 3,250 Californians with developmental disabilities will be educated/trained in multiple languages regarding employment options, incentives and resources.

EM1.4 By September 30, 2011, the Council will advocate for introduction of career possibilities curriculum for all children in regular and special education by age 10.

EM1.5 By September 30, 2011, 500 consumers, family members, providers and employers will be educated/trained on assistive technology for the workplace.

EM1.6 By September 30, 2011, the Council will collaborate with appropriate entities to achieve the system reforms contained in SB1270.

How will the Council report/measure its success?

EM01: The number of adults whom have jobs of their choice through Council efforts.

EM02: The number of dollars leveraged for employment.

EM04: The number of business/employers employed adults.

EM05: The number of employment programs/policies created/improved.

Health

Why is this important?

People with developmental disabilities have limited access to primary care, specialist and dental care due to Medicaid reimbursement rates. Mental health services for people with developmental disabilities are difficult to access, not only due to funding, but often from mistaken beliefs that people with developmental disabilities can't benefit from mental health services. Health care services and funding, especially federal funding, is in a state of flux. People need information and education to stay informed and manage potential changes. People with developmental disabilities have limited access to physicians and clinicians who understand their condition. People with developmental disabilities have limited access to medical offices and equipment that are physically accessible and that accommodate their needs. Prevention is critical. People need to learn about Fetal Alcohol Spectrum Disorders and other issues that can assist in prevention or lessen the impact of a disability. People with developmental disabilities need access to information and activities that promote healthy lifestyles.

Health Goal 1:

Californians with developmental disabilities will have access to a full range of coordinated health, dental, and mental health services in their communities.

How will the Council try to achieve this goal?

HE1.1 By September 30, 2011, the Council will promote policies and programs to educate physicians and clinicians on developmental disabilities on how to best provide appropriate health, mental health, and dental care for consumers.

Health Goal 2:

Californians with developmental disabilities have control, choice, and flexibility over their health care.

How will the Council try to achieve this goal?

HE2.1 By September 30, 2008, 3,250 Californians with developmental disabilities and their families will be educated on Medi-Cal managed care and be able to make informed choices as a result.

Health Goal 3:

Californians will achieve optimal health and wellness through the prevention of primary and secondary causes of disabilities and promotion of healthy lifestyles.

How will the Council try to achieve this goal?

HE3.1 The Council will educate at least 100 policymakers, public officials, and health professionals per year on the importance and need for universal developmental screening for all children.

HE3.2 By September 30, 2008, the Council will work collaboratively to launch a major statewide campaign to educate the public on the dangers of drinking while pregnant.

HE3.3 By September 30, 2008, the Council will collaborate with the Governor's office and other state agencies on programs and projects that maximize health and wellness, including physical fitness, nutrition, and obesity prevention.

HE3.4 By September 30, 2009, the Council will educate juvenile court judges, probation departments, mental health and social service agencies, educators, and regional centers in at least eight Counties on Fetal Alcohol Spectrum Disorders (FASD), its prevention, associated secondary disabilities, diagnostic information, local resources, interventions, and best practices.

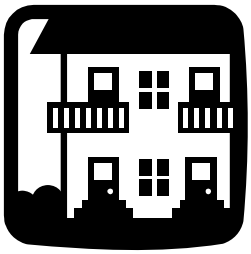
HE3.5 By September 30, 2008, the Council will establish at least one consumer peer-to-peer project to educate consumers on achieving optimal health through physical activity, healthy lifestyles, proper nutrition, and obesity prevention.

HE3.6 By September 30, 2007, the Council will advocate for at least one State-funded research grant related to Alzheimer's and Down Syndrome.

How will the Council report/measure its success?

HE01: The number of people who have needed health services through Council efforts.
HE02: The number of dollars leveraged for health services.
HE03: The number of health care programs/policies improved.
HE05: The number of people trained in health care services.

Housing



Why is this important?

California has one of the highest costs of living in the nation, making it hard for consumers to qualify for ownership or even rental housing without assistance. The need for accessible and affordable housing far outstrips the supply. Social Security policies regarding accumulation of savings make it difficult for consumers to save money toward the purchase or maintenance of a home.

Housing Goal 1:

Californians with developmental disabilities have access to affordable housing that provides control, choice, and flexibility regarding where and with whom they live.

How will the Council try to achieve this goal?

HO1.1 By September 30, 2011, 3,250 Californians with developmental disabilities and their families will have information and training in multiple languages on affordable/accessible housing.

HO1.2 By September 30, 2011, 500 units of affordable/accessible housing will be available to Californians with developmental disabilities through Council efforts.

HO1.3 By September 30, 2011, 200,000 Californians with developmental disabilities and their families throughout the State will receive information on Council-funded online Statewide Housing Program Locator.

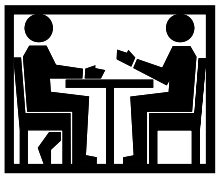
HO1.4 By September 30, 2009, the Council will advocate for California to apply for a Social Security waiver allowing individuals with developmental disabilities to save up to $10,000 in the bank.

What will the Council measure to report its success?

HO01 The number of individuals who have homes of their choice through Council efforts.
HO03 The number of dollars leveraged for housing.
HO05 The number of individuals housing programs created/improved.
HO06 The number of units of affordable, accessible housing made available.
HO08 The number of people trained in housing.

Quality Assurance

Why is this important?



This Area of Emphasis is mandated by the federal Administration on Developmental Disabilities (the federal definition of quality includes self-advocacy). The other goals within Quality Assurance are based on identification of current issues and public response.

Quality Assurance Goal 1:

Individuals with developmental disabilities and their families have control, choice, and flexibility in the services they receive.

How will the Council try to achieve this goal?

QA1.1 By September 30, 2008, 200 people with developmental disabilities and their family members will receive intensive leadership development training to enable them to successfully hold leadership positions at the state and local level.

QA1.2 By September 30, 2011, the number of Californians with developmental disabilities who participate in self-advocacy groups will increase by 10% per year.

QA1.3 By September 30, 2011, 10,000 individuals with developmental disabilities will gain the skills and supports to advocate on their own behalf and for their peers.

QA1.4 By September 30, 2011, 10,000 family members of people with developmental disabilities will gain the skills and supports to advocate on their own and other families' behalf. At least 10% of these will have a primary language other than English.

QA1.5 By September 30, 2011, 13,000 individuals with developmental disabilities and their families will have improved access to timely and accurate multi-lingual and easily understood culturally competent information about self-directed services and other new initiatives.

QA1.6 By September 30, 2011, 13,000 people with developmental disabilities and their families will have improved access to an array of quality services of their choice through Council legislative and other advocacy.

QA1.7 By September 30, 2011, 1,000 consumer and family members will participate in social/support groups of their choosing, based on mutual interest and support.

QA1.8 By September 30, 2011, the State Council will utilize Life Quality Assessments and other activities to identify and eliminate systemic barriers and promote systemic improvements.

QA1.9 By September 30, 2009, the State Council will develop easily understood information about the services system and consumer and family rights and will post it to the web in at least 10 languages.

QA1.10 By September 30, 2011, the State Council will collaborate with DDS to implement an Interagency Dispute Resolution Pilot Project that improves timely access to services.

Quality Assurance Goal 2:

Californians with developmental disabilities are free of abuse, neglect, or exploitation, and are provided equal access to protection and legal remedies when those rights are violated.

How will the Council try to achieve this goal?

QA2.1 By Sept. 30, 2009, the State Council, through the "Abuse Victims with Disabilities Think Tank" will develop system recommendations to reduce the incidence of abuse of children with developmental disabilities and improve response services for victims.

QA2.2 The Council, in collaboration with its federal DD Act partners (PAI, USC and UCLA), will continue advocating for implementation of the recommendations contained in its joint report, "Abuse and Neglect of Adults with Developmental Disabilities: A Public Health Priority for California."

How will the Council measure/report its success?

QA01: The number of people benefiting from quality assurance efforts of the Council
QA02: The number of dollars leveraged for quality assurance programs in community placements.
QA03 The number of quality assurance programs/policies created/improved.
QA04 The number people facilitated quality assurance.
QA05 The number of people trained in quality assurance.

QA06 The number of people active in systems advocacy about quality assurance:
Break out the number:

- QA0A The number of Self-advocates active in systems advocacy about quality assurance.
- QA06B The number of Family members active in systems advocacy about quality assurance.
- QA06C The number of others active in systems advocacy about quality assurance.

QA07 The number of people trained in systems advocacy about quality assurance.
Break out the number:

- QA07A The number of Self-advocates trained in systems advocacy about quality assurance.
- QA07B The number of Family Members trained in systems advocacy about quality assurance.
- QA07C The number of others trained in systems advocacy about quality assurance.

QA08 The number of people trained in leadership, self-advocacy, and self-determination.

QA09 The number of people who attain membership on public and private bodies and other leadership coalitions.

Recreation

Why is this important?

The selection of Recreation as an Area of Emphasis was based on extensive public input regarding the importance of social and recreation opportunities in achieving community inclusion.

Recreation Goal 1:

Californians with developmental disabilities of all ages will have full access to and inclusion in community social and recreation programs.

How will the Council try to achieve this goal?

RE1.1 By September 30, 2011, 500 Californians with developmental disabilities will participate in community social and recreational opportunities of their own choosing through Council efforts.

How will the Council measure/report its success?

RE01: The number of people active in recreational activities through Council efforts.
RE02: The number of dollars leveraged for recreation programs.
RE03: The number of recreation programs or policies created or improved.
RE05: The number of people trained in recreation.

Transportation

Why is this important?

Most people with developmental disabilities rely on public transportation (and Paratransit) to access their community. Public transportation is not available at certain times or certain days in many locations. This, in turn, can further limit access to employment and healthcare. The time spent on public transportation is often too long for the distance traveled due to routes and transfers. Paratransit is unreliable and often it is difficult to coordinate when crossing catchment areas.

Transportation Goal 1:

Californians with developmental disabilities and their families will have access to transportation that enables full participation in all aspects of community life.

How will the Council try to achieve this goal?

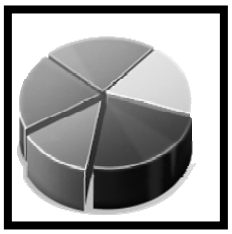
TR1.1 By September 30, 2009, the Council will develop a coordinated transportation system model that serves the needs of people with developmental disabilities through public/private collaborative efforts.

TR1.2 By September 30, 2011, the Council will replicate the coordinated transportation model in at least one other area.

How will the Council measure/report its success?

TR01: The number of people who have transportation services for work, school, medical, and personal needs.
TR02: The number of dollars leveraged for transportation programs.
TR03: The number of transportation programs or policies created or improved.

Cross-Cutting



Why is this important?

The Administration on Developmental Disabilities has also required the Council to add a "cross-cutting" area. This is for activities that impact equally across all the Areas of Emphasis, such as the Council's intention to undertake a major public awareness campaign on developmental disabilities.

Goal 1:

The Council will use community education and awareness to shape public policy that positively impacts Californians with developmental disabilities and their families.

How will the Council try to achieve this goal?

CC1.1 By September 30, 2011, one million Californians will be educated on the abilities and strengths of individuals with developmental disabilities.

How will the Council measure/report its success?

CR01: The number of public policymakers educated by Council about issues related to Council initiatives.

CR02: The number of copies of product distributed to policymakers about issues related to Council initiatives.

CR03: The number of members of the general public estimated to have been reached by Council public education and awareness.

Public Input and Review

The 2007-2011 Plan was developed with extensive public input, involving more than 1000 Californians in one way or another. The Council and each Area Board conducted identical Educated Informant sessions to identify the highest priority issues in their local areas. A workgroup compiled common themes from these sessions and each Area Board conducted 1 or more focus groups to confirm that the top themes resonated with the community. Based on this, SCDD drafted goals/objectives that were released for public review/comment. SCDD conducted 7 formal hearings around the State, including 2 specifically for self-advocates. In addition, several boards held informal Plan input sessions in conjunction with meetings in their areas. The Draft Plan was also posted to the SCDD website. Initial response was so strong that additional goals/objectives were proposed and released for public comment. On July 18 the Council reviewed the Final Draft and authorized submission of this 2007-2011 State Plan.

For FFY2008: In accordance with Federal Law, The California State Council on Developmental Disabilities provided for a 45-day public review and comment period on its proposed Plan amendments. This year's Review and Comment Period was for the period from, June 15-July 30, 2007. The Council sent notices of proposed Plan Amendments to approximately 600 agencies and interested parties. During the public comment period, an average of 648 visitors per day viewed the Council's website and had access to information on the proposed amendments. The specific webpage about the proposed changes and the public comment process was viewed 332 times. Two public hearings were held – one in Northern California and one in Southern California. Only a few people spoke at each one. Likewise, only a small number of written comments were received. While the exact reason is not known, this is consistent with previous annual updates, where the fewer the substantive amendments proposed, the fewer the number of comments received.

Most public comments were affirmations of 2007 Plan issues addressed. Of the few requested modifications, SCDD adopted nearly all suggestions. The only suggestions not adopted were those determined to be already addressed, or where an individual was expressing a personal opinion that was not consistent with adopted SCDD policy.

The topic of underserved populations and language barriers generated the strongest response, both in terms of numbers and intensity. It is clear that this is a critical issue to the responders. Several comments were received about the service system and a belief that the Council has not done enough in the area of outreach to underserved populations, not only for those who have language barriers, but consumers with developmental disabilities who also have other disabilities, especially those who are deaf and/or blind. Moore than one responder stated that traditional services for those who are deaf and/or blind fall short of meeting the needs of those who also have cognitive limitations.

Public Evaluation of the Plan

The Federal Government asks the Council to summarize its Plan for monitoring, reviewing and evaluating the State Plan at least annually.

The Council considers the Plan the blueprint for its activities and is informally reviewing, monitoring, and/or evaluating the Plan on a continual basis. This occurs at both the full Council level, and through its Program Development Committee. The development and production of an annual PPR, together with the annual Plan update due each August, provides a twice-per-year formal review of the status of Plan implementation. An additional, informal review of the Plan occurs each year when the objectives for consideration of grant funding are selected. The analysis leading to this selection includes a review of the implementation status of all Plan objectives.